



## WORKING WITH A DISSOCIATIVE DISORDER DIAGNOSIS



by Sue McAteer

I have worked with a number of dissociative clients over the years, several of whom have had full-blown dissociative identity disorder along with a significant number who have struggled to get a satisfactory diagnosis but whom we might label dissociative disorder not otherwise specified (DDNOS), now called other specified dissociative disorder (OSDD). I think the best preparation for working with dissociative clients is working with any clients – they are not a different species of being, but just the same as me and you and anyone else. They've simply experienced worse things (the worst things), and their brains have had to make greater adaptations to that.

Once we understand dissociation as a logical response to overwhelming trauma, it stops being so dramatic and different, and the person suffering dissociation stops being 'complex' and 'bizarre' too. There is nothing bizarre about dissociative

disorders – what is bizarre is how some people can be so badly mistreated that they end up with a dissociative disorder. It seems that as a society we pay very little attention to that, and focus instead, with morbid curiosity, upon 'mental illness' which in so many cases would be so much better understood as 'mental distress'. 'Mental illness' sounds as if they have been afflicted by something, as if their brain has gone wrong, but 'mental distress' is really all we're talking about. I firmly believe that we shouldn't pathologise suffering, and call people 'ill' when they are simply experiencing the natural fallout of trauma.

I think it's something that has been instilled into our consciousness, with an emphasis from the medical model, that everything we suffer should have a name and be called a syndrome or a disorder. It's as if we can only cope with our suffering if we alienate it and call it names. For some people, a diagnosis is a relief – what



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they have really been battling with is a terrible fear of going mad, and being told instead that their symptoms represent 'unhealed suffering' (as Carolyn Spring puts it) comes as a massive relief. To others, a diagnosis makes them feel validated, that it's words on a bit of a paper that tells the world that there really is something wrong with them, and they're not making it all up.

Many people expect a diagnosis to usher in the right treatment – most of them are disappointed and can actually find that it excludes them from treatment. So I have found that a diagnosis is a double-edged sword, and for all its benefits it also comes with a long list of disadvantages – difficulties in obtaining insurance, the possibility of losing a driving licence, other people's prejudices and ignorance, employment difficulties, to name but a few. I think it's always worth weighing up the whole concept of a diagnosis and thinking, 'Do I really need this? Is it going to make a difference?' For some it does and so it's a good thing, but many people seem to think that they need a diagnosis in order to recover, which is simply not true.

The best response to a diagnosis of dissociative identity disorder, in my experience, is to use it to validate your symptoms and your experiences, but to hold it lightly. It describes your experiences (and you could say that within that it points to a likely cause) but it doesn't define you. The worst response to a diagnosis is to 'become the label' – to

think, 'This is who and what I am, so I need to find out what people with DID are like and then become like them.' That may not be said or done at a conscious level, but it's a very real possibility for people who have grown up with a sense of identity confusion. The pull to fit in, to belong to a group (especially in the absence of a nurturing family environment), can mean that people twist themselves out of shape and become what they think people believe they are, rather than having an 'internal locus of evaluation' and being who they really, truly are and having sufficient ego strength to stand firm against peer pressures. It's the same thing as goes on during adolescence, although delayed due to trauma for many with a dissociative disorder.

A diagnosis to me is a map of the territory rather than the destination. It tells me as a therapist what to look out for. It suggests quickest routes, and warns me of dangers. But I must never believe the map over and above my experience of the person in front of me. It's a form of prejudice, and perhaps even discrimination, if I look at people through the lens of their diagnosis. Who's to say that that diagnosis is correct, anyway? How many people have been given a diagnosis, for example, of borderline personality disorder (or emotionally unstable personality disorder) by a psychiatrist that they have only met for 10 minutes? That diagnosis, so quickly given by an 'expert', can haunt them for the rest of their lives, follow them on their medical history,



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and cause professionals to treat them with wariness and suspicion. That's a huge responsibility therefore to dish out diagnoses so quickly and to rubberstamp them as 'facts'. I think it's much safer to think of a diagnosis in terms of a theory, a hypothesis, and to weigh up its suitability as things develop, but always be open to changing it if it doesn't fit, or if it doesn't help.

A diagnosis can be helpful, but most of the time – at least for me personally – I see it as something that just gets in the way. This person, who has been brave enough and determined enough to make the effort to come and see me, despite their shame, their fear and often their physical or logistical problems – is a person, first and foremost: a person just like me. They may have suffered extensive trauma as a child, which may be affecting the way their brain operates now because they're still trying to keep themselves safe, but that doesn't affect who they are as a person.

Given the abuse of power that so many survivors have experienced, I think it's essential that I don't infer a power imbalance between me and this other person by treating them as 'other' – by thinking of them in terms of a broad brushstroke label. I am not the 'expert' – they are the expert on them. I can guide them, and help them to navigate their way through their difficulties, but they're in the driving seat and the moment I think I know them because I know their diagnosis, I am not just a useless guide,

but I'm exerting power over them too. It's the power to determine someone's identity, and I believe that each individual person alone has the right to determine that, and that we shouldn't be imposing that on other people for them.

I work with the person in front of me at the time – I don't work with their label. I want to show them that I respect them, that I value them, that they have worth and dignity, and that I'm not better than them or more powerful than them. I won't always achieve that, but I can try, and it's always my intention. I want the person in front of me to know that I'm not 'better' than them just because I don't have flashbacks, or don't switch between parts of my personality, or don't self-harm. If I had had their experiences, I would probably have their symptoms too! I've just been lucky enough to have avoided the kinds of trauma that they had no choice but to endure. I've been lucky enough to have grown up in a family where I was loved, and I knew it. That is a massive privilege and blessing, but it doesn't make me a better person. And yet every single client I have ever worked with has felt that I'm better than them, at least at the beginning, by default. That's part of the legacy of trauma and abuse – people feel worthless and ashamed and undeserving, and they come to therapy feeling bad for taking up our time, for 'making a fuss'. I have to work hard at levelling the playing field between us.

When I was first a therapist, I used to think that I had to inspire and encourage



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my clients to think and feel what I was thinking and feeling. After all, I'm happy, life is good, I feel blessed – and I want to pass that on. Eventually I realised how arrogant and wrong that was of me. It's not about me, and it's certainly not about me pulling someone else up to my level, or getting them to think like I think. That's a throwback to our colonial history, where as the whites ruling the world we went to educate the savages who became our slaves. That kind of 'racism' still goes on between professionals and their clients nowadays, far far too much.

I should be focused on understanding what my clients think, and why they think it – because there will be a good reason for it, a reason usually based on survival or adaptation to their environment. It will help me understand them, and then I can help them understand themselves. Once people understand that the way they are makes sense – that it's logical in the light of their past experience – they tend to be able to be much more compassionate towards themselves. I often find that survivors' biggest battle is to stop perpetuating the abuse. They've grown up with neglect or abuse, and they think that that's the only way to be, so even when in adulthood they are free from their abusers (to one extent or another), they take up the role of abuser towards themselves. It maintains the status quo, fits their expectations, and feels right, even though they hate it.

To start with I used to try to argue this out with my clients, to help them see that

they don't need to continue to abuse themselves, that they can have good things now, but I was surprised at how ineffective it was. In more frustrated moments I would blame the client for this (not necessarily to their face!) and talk in terms of them being 'resistant'. But now I understand much more that what I am asking of them is ridiculous, and even a little bit arrogant of me. Why on earth should they trust me or believe that I'm right when I say that they are lovable and worthy of care and attention, and that they deserve good things? Nothing in their experience has ever suggested that that could be the case, and I sit there with them for an hour or two a week and tell them in effect how wrong they are to believe what they believe and that they should believe what I do! – and then I'm surprised when we don't get anywhere. So often as therapists we blame this on 'resistance' when really it's our own lack of empathy: we fail to see the world from their viewpoint.

I've found it's much more effective just to hear my clients – really hear them – and delve deeply with them into their own experience, and just to 'notice' it, to bring to conscious attention their beliefs and their fears, but without trying to change them. I don't have the right to change them – only they do, so it's not my job to tell them that they should. It's my job to help them see what it is that they believe, and how they feel, and then to decide for themselves if they want to change that. Most do. Some need a lot of time, patience and understanding



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before they can begin to really dare to look at this stuff honestly, and realise how miserable they are with their lives, and to dare to hope that things could be different. I'll make things worse if I rush that process – but often the constraints of mental health services means that people have 6 sessions or 6 months and they don't have the time to begin to feel safe and start to explore.

Attachment theory teaches us that exploration comes from a secure base, but many of our mental health services are not geared up to provide that secure base. Working in private practice I can give my clients the time to work at their own pace, and I've found that when people aren't shamed or told that they're wrong and urged to change, they can learn to stop beating themselves up for being 'defective'. The basis for all change, I believe, is a profound respect for them as people, that they have survived the most awful things in the past, and they're doing the best to survive now. When they realise that I'm not looking down on them, that I'm not patronising them, but that I do actually deeply respect them, that often sparks a change in their attitude towards themselves. They begin to believe that they're not stupid. They begin to think that things can change, and that they have the power and the capabilities to effect that change. But change doesn't come by me shaming them and inferring that they're not good enough because they don't think and feel like I do!

That's why I resist a 'diagnosis'. If people believe that they are their label, it's hard to come out of it. If instead we could give people diagnoses of 'extraordinary resilience in the face of adversity syndrome' or 'coped with too much trauma in childhood syndrome' then they might see themselves in a more positive light. Telling them that they are defective and disordered as people because they were chronically abused or neglected just isn't fair on them. It blames them, rather than celebrating their strengths and what they have survived. When I hear my clients' accounts, I'm not sure I could have managed in the way that so many of them have – I don't know if I would have kept on battling to stay alive and get treatment in the face of so much prejudice, apathy and blame.

A diagnosis remains useful as an explanation, and I have no hesitation in using it to help people understand why they act and react why they do. But it still seems to me that dissociative identity disorder is the diagnosis that no one wants to give, while some psychiatrists are all too quick to misdiagnose with schizophrenia or borderline personality disorder – the diagnoses that no one wants to receive. The real benefit of being a counsellor or psychotherapist in private practice is that we can work with the person in front of us, rather than being constrained by labels and controlled by the system that imposes them. ●

